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ABSTRACT

Discussed in general terms are various impediments to provision of services to the mentally handicapped through community mental health programs. The authors first state the most community health programs are ineffective in that they essentially ignore planning and provision of services to mentally handicapped persons. Then the authors attempt to determine reasons for the under-utilization of community health program resources. Probable reasons for lack of services discussed include: the social stigma attached to being mentally handicapped; patterns of American culture; attitudes of professional persons; attitudes of psychiatrists and psychiatric services; influences of various volunteer agencies; and systems impediments. In conclusion, guidelines are presented for designing a service delivery system, which include: define, analyze, and quantify problem; formulate solution; identify, quantify, and inventory resources required to implement solution; determine extent to which additional resources are required; develop information base that will justify allocation of necessary funds; recruit additional resources; implement solution; and evaluate solution. (CB)

What Impedes the Provision of Services to the Retarded Through Community Mental Health Programs*

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ABSTRACT

The vast array of community mental health programs, which in the aggregate constitute a treatment resource of huge proportions, virtually ignores planning or actually providing services to mentally retarded persons. The under-utilization of this resource is a problem deserving greater attention. This paper discusses some of the major problems impeding provision of services to the retarded through community mental health programs. Discussed are such items as the nature of retardation, patterns of American culture, attitudes of professional persons, some influences by volunteer agencies, and a method of system design.

*This paper is a condensation of a symposium presented by the authors in Washington, D. C. on May 29, 1970 at the 94th Annual Meeting of the American Association on Mental Deficiency.

What Impedes the Provision of Services to the Retarded Through Community Mental Health Programs*

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The federal government is presently in the midst of establishing a vast array of community centers for the mentally ill. Many states have already established their own networks of community mental health services. For example, both New York and California have had active community mental health programs for over a decade. Presented with these vast resources, and the concomitant long-standing and critical lack of community services for the mentally retarded, the question naturally arises: "What impedes the provision of services to the retarded through community mental health programs?"

The American Psychiatric Association has gone on record in unequivocal terms in more than one official position paper regarding the place of retardation services in mental health programs. For example, in October, 1962, the APA stated that the new community mental health programs should extend their services to the retarded as a matter of routine. In 1966 the APA Council stated, "When a community has an accepted mental health clinic it should be strengthened by the addition of a specialist so that it can provide comprehensive services to the retarded" (APA, 1966). The Council further noted that the special Diagnostic and Statistical Manual was inadequate as it related to mental retardation. A revised Manual was published in July 1968 and its coverage of mental retardation was substantially expanded.

The American Psychological Association in an official position paper urged psychologists to take a leadership role in programs for the retarded. Noting that "mental retardation is primarily a psycho-social and psycho-education problem" it suggested that "the time is ripe for a concentrated psychological approach to the problem of retardation" (APA, 1970).

Why is it, then, that in spite of the great need for community services for the retarded, and the apparent interest in providing such services on the part of the American Psychiatric Association, the American Psychological Association and

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other professional disciplines, that services for the retarded in community mental health programs are not generally provided? Furthermore, why is it that services are provided in some local mental health programs while no services are provided in others which appear to be comparable?

There are both attitudes and practical problems which impede the development of more programs for the mentally retarded in local communities. One significant impediment is that public health administrators and psychiatrists directing local mental health programs do not agree on the appropriateness or feasibility of having mental retardation services included in their mental health program. The attitudes of the consumers themselves (that is, the families of the retarded) at times also inhibit initiation of such programs.

Most mental retardation services have traditionally operated from the state level, and Federal money has only recently become available. At present the big push is to have mental health services operated at the local level. Thus created is a strong possibility that retarded persons may be left in a vacuum because local services are not in the habit of planning or providing services for retarded persons, or being expected to do so. This paper will address itself to some of the major problems impeding a fuller provision of services.

1. Items pertaining to the retarded themselves.

By the time the term "retarded" has been applied to a person, unless he has some obvious physical disfigurement, it is very likely that his inability to understand abstract matters may have been the single most influential point in his receiving the designation of "retarded." Many retarded are physically disfigured in one way or another. Only limited goals are practicable when working with the retarded. As a group, retarded persons are less likely than are many other handicapped groups to attract persons to work with them because of the potential emotional rewards.

For many years retarded persons were all too customarily shipped away to be confined in large institutions. This isolation has kept both "professional" and "lay" people from being more conversant with the retarded as well as more tolerant of them.

The mythology about the retarded has many negative aspects and inaccuracies that tend to persist through the years. You will find it difficult to think of statements referring to mentally limited people which do not have contemptuous and rejecting connotations. Probably the more pernicious aspects of the mythology

about retardates are the most devasting; e.g., "You can't teach them." Supposedly it was never intended to make such implications in those discriminatory terms "educable" and "trainable," but in addition to the evils inherent in all dichotomies, this one can be construed to imply that some retarded cannot be taught at all.

The mythology of the retardate has at times been heavily entangled with the concept of juvenile delinquency.

To many persons, most of whom are not aware of it, retardation is threatening because it implies that the retarded have less control over socially unacceptable sexual or aggressive impulses. Since people can hate, in others, unacceptable parts of their own personalities, the retarded can be threatening without the observer being aware why. What part of our self is more unacceptable to us than a physical disfigurement, clumsiness, stupidity, social ineptness, or insensitiveness to what is going on around us? (Becker, 1964).

2. Items pertaining to the American culture.

The general tendency of the American culture to reject and isolate retardates has strong roots in cultural biases. The "success and achievement" orientation of American culture discriminates against all handicapped people, more so with retarded because most people think the "M.R." condition is immutable. The retarded as a group, for all that we would like to think so, are not yet well accepted. The term "mentally retarded" was originated in order to get away from negative aspects of terms such as "imbecile." However, in a relatively short time the initials "M.R." have come to be used loosely as an epithet by school children to indicate opprobrium regardless of the presence or absence of handicaps. In such ways does our culture reveal itself (Orpack, 1969; Ramo, 1969).

3. Items pertaining to professional persons generally.

The majority of professional persons now practicing in the nation (and surely more so for physicians) were trained when didactic information about retarded persons or exposure to them in clinical years was not included in the course of study. Professionals, being human, are likely to feel threatened by patients with problems for which their previous training and experiences has not prepared them. Where the condition is perceived as a static or "hopeless" one, the feeling of threat and inadequacy may be even more accentuated. The professional person can be in the most lamentable position of "not knowing that he does not know" how to deal with problems involving mentally handicapped persons (Begab, 1970).

4. Items pertaining to psychiatrists and psychiatric services in particular.

Most professional persons in mental health services are highly verbal and want to spend much of their time treating patients who are "good candidates for psychotherapy," which concept, as usually employed, does not fit mentally limited persons. Although many psychiatric facilities have a stated policy of "developing the fullest potential" of each patient, many professional persons, if not most, are reluctant to take mentally retarded patients. The professional person in a psychiatric service often sees himself as working with the unlovable and the difficult, and yet he many have no anxiety about excluding the retarded.

To test this hypothesis one of us called the director of a psychiatric clinic in a relatively small county to ask what services are offered for the retarded. He answered, "No," and paused for a moment. Stammering for a few seconds, he continued, "X agency has been handling some of those people [note the wording]. We might see some of them in consultation, but not therapy. We might see them about medication, but they are not amenable to psychotherapy." Pushing to end the conversation, he suggested that the caller contact X agency. Note that he was asked what services the clinic offered the retarded, and he could only talk about psycho-therapy. It is safe to say that this kind of response is what one would hear from a psychiatric clinic.

Until very recent years it was rare indeed that any community psychiatric service programmed any activity whatsoever either specifically for retardates or available to them on an equal basis with non-retarded.

Further discrimation against retarded persons may happen as a by-product of official policy of a clinic to deal with brief interventions only. Such a policy in itself tends to exclude services to retardates, which may be dismissed in advanc as being "long term."

One indication of profession "involvement" with a subject is the number of articles which appear in journals. It is really noteworthy when any psychiatric journal prints a paper concerning mental retardation.

5. Other matters not readily fitting into the preceding categories.

As a result of disappointment with psychiatrists, parents and parent groups as official bodies, have turned in disillusionment to pediatricians, public health workers, and others who are willing to work with retardates. The lack of professional preparation of psychiatrists by both training and experience sometimes

becomes painfully evident to parents or other "friends of the retarded," many of whom have informed themselves with remarkable completeness by means of the excellent materials now available.

The limitations on funds from official sources always result in some competition between programs. Mental retardation programs strongly tend to come off second or third best when the chips are down.

6. Voluntary Association Impediments:

Although voluntary associations have sometimes served a key determining role in the acquisition and provision of services for the retarded, some of their patterns of functioning have actually impeded the provision of services.

The current emphasis of the National Association for Retarded Children is to generate and support services and programs by public and other private organizations and not to provide services through the national agency or its units. This emphasis conflicts with that of many agency members who have a strong emotional need to create direct services for the immediate needs of the retarded, and are comparatively uninterested in urging the development of service programs by official agencies. While both activities are legitimate and necessary in the interest of the retarded, it is necessary that the voluntary agency emphasize the role of serving as a vehicle and catalyst for obtaining the full spectrum of service needed for the retarded population.

In the interpretation of its objectives, the national agency has set priorities regarding the "obtaining of" and "providing of" services to the retarded in the local community. The agency has stated that there are only two conditions under which the local unit would be encouraged to operate its own service programs. The first is to innovate, demonstrate, or experiment with new and different programs. The second is to operate programs when there are no other agencies taking the responsibility for operation of the program. In relation to psychiatric and other services provided in a local mental health center, usually neither of these two conditions is met. If either or both of them are, that is, if there is either a need for innovation or no other agency is likely to take responsibility, it is still much too expensive a program to be run by a local voluntary agency. Many local units are too busy running small programs to take advantage of the opportunities to promote big programs operated by public agencies.

Probably the description of a "typical" local Association for Retarded Children would be impractical in view of the wide diversity of approaches to the

common problem of mental retardation. Each unit, in actuality develops a "life-style" that meets the needs of the retarded population to the degree possible while also meeting the needs of the members of the local unit to provide and obtain services. The unit's life-style will vary according to the makeup of their membership, the support of the local community and the group's ability to attract funds for their operation. If service programs are offered or obtained, they will vary according to the financial capacity of the group and the wishes of the memberships as to what services they wish to offer or obtain. On the assumption that there are important similarities between local voluntary units, the following can have relevance to our question.

The California Association for Retarded carried out a study designed to obtain information regarding membership and operation. Although CAR was formed with the prime purpose of serving all of the retarded, the study revealed that parents with severely or moderately retarded children make up 77% of the total membership. It was also found that CAR is not representing the younger families, a group of great importance because parents need counsel as soon as possible after the child is diagnosed as mentally retarded. Since the mildly retarded (the vast majority of the retarded) might most profit from psychiatric and other services provided in a local mental health setting, their gross under-representation in local voluntary agencies may impede the provision of such services.

CAR also has only a small number of parents from minority groups and lower socio-economic backgrounds even though these areas have been shown to have a disproporationately large incidence of mental retardation.

A recent study considering why the preponderance of research money has been devoted to research on organic causes of retardation noted that the membership of politically powerful citizen's advisory committees was drawn from upper-middle and upper class citizenry whose retarded children were more apt to be retarded dut to organic causes rather than economic or social conditions.

Many parents see a stigma attached to "mental illness" and are reluctant to see services and programs offered to their child through the auspices of a psychiatrically oriented setting such as a community mental health program.

The authors believe that there is a danger inherent in the transfer of <u>all</u> programs to the public sector. Some services are better done by the private sector and people should not be denied the opportunity of serving their fellows as private individuals.

Additionally, the public image of local associations will change. No longer can a contributor point to a building and say, "I help that program." Raising money in the community becomes more difficult. Without additional funds, there is no operating capital to hire professional staff. The support payments to both the state and national "parent" organizations are reduced due to lack of income. The unit would then have to go back to a totally volunteer movement. Not necessarily bad, perhaps, in the eyes of some, but in reality the day-to-day continuity that is provided by professional staff in addition to their expertise, can often make the difference between a local unit being just a name in the community or a power to be respected.

As the vanguard of the public interest in a special health problem, it has been inevitable that the voluntary agency would see the need for public health services which are not currently available. The voluntary agency, in its zeal to obtain much needed services for retarded persons, sometimes impedes the ultimate development of such service by starting them with its own limited resources and continuing over-long to operate them often keeping all its eggs in this one basket. This situation subtly but potently deters the important on-going work of stimulating government to provide various kinds of services with its much greater resources.

7. Systems Impediments:

There are further impediments to the provision of services to the mentally retarded through community mental health programs which are generic, related to the delivery system, and inherent therein. Here we find the same deficiencies that exist in other systems of providing health care, education, public assistance, manpower development and rehabilitation services. Services are fragmented with duplications and gaps; rivalry between competing providers of service for the primary responsibility of program administration and the list goes on.

We cling to traditional concepts of delivering service long past the time when it becomes obvious that they are no longer appropriate or adequate. We resist innovative ideas. We exclude from the planning, decision-making, provision and access to service, those segments of the population with the highest incidence and the greatest need. Our informational base is inadequate and it is charitable to call our planning of services archaic. Anarchic might be more appropriate.

The end result is a pattern of providing services to the mentally retarded

that should embarrass any modern, industrial nation, much less the richest nation in the history of mankind.

8. Designing a Service Delivery System:

It is possible to design an adequate system for the delivery of services to the mentally retarded. The approach is a generic one. It is equally applicable to the mentally retarded, nursing mothers, the mentally ill or any target population you choose.

The approach can be and must be generalized to the delivery of health services. It is in fact a specific case of programming services to meet human needs (Chacko, 1969; Halpert, et.al., 1970; Whiting, 1969).

The steps, more or less in sequence, involved in the design of such a system can be listed thus:

1) Define, analyze, and quantify the problem,
2) Formulate solution(s),
3) Identify resources required to implement solution(s),
4) Quantify resources required to implement solution(s),
5) Inventory resources available to implement solution(s),
6) Determine extent to which additional resources are required,
7) Develop information base that would justify allocation of the required additional resources,
8) Recruit the additional resources (or failing this, reformulate solution(s) and recycle until resources are adequate),
9) Implement solution(s) (or simulate model),
10) Evaluate solution(s); and (11) Recycle.

This listing may strike some as simplistic. It is. It ignores, for the moment, two sets of complicating factors.

This first set is extrinsic and relates to the social climate in which the effort is undertaken. It includes attitudes about what constitutes an acceptable expenditure of funds, feelings at all levels about mental retardation and the retarded, tribalism among warring professionals, territoriality among providers of service, stratification among the retarded, by degree and manifestation, exclusion of the population with the highest incidence from access to service and a wealth of other characteristically human obstacles to rationality.

The second set is intrinsic and relates to the difficulties inherent in collecting, analysing and interpreting data and formulating rational conclusions

compatible with reality. These compound the problem. They are factors that must be taken into consideration and dealt with. They do not, however, preclude the successful design of a system, and if adequately dealt with, will facilitate implementation. To ignore them is to ensure failure.

The extrinsic factors are subject to analysis very similar in some respects to that employed in the design of the system. In this instance, the analysis is applied to those forces that tend to reinforce or to inhibit the development of the system. This technic is known as force field analysis. It identifies the supportive forces, factors that favorably influence these forces, those that exert an unfavorable influence, and the predicted net effect of these interacting factors.

In community mental health work this brings us to more familiar ground. The relevant technics are: community organization, public information and education, advocacy, lobbying, button-holding and all the other means of influencing the decision-making process, in the public arena and in private encounters. The most important technique is the development of an information base that would support a rational and realistic decision favoring the system proposed.

This information becomes the major input into the variety of techniques listed above. The second set (intrinsic factors) interacts with the level of skill of the systems analyst, to determine the degree of sophistication of the system design.

In a small community, the prospects of finding a skilled systems analyst are poor, but the dimension and complexity of the problems are of an order that will yield to a relatively simple analysis, and be amenable to a relatively simple treatment. The crisis situations exist in large urban centers, where the problems present every complexity imaginable.

The systems analyst must have competence in at least two areas -- systems engineering and a working knowledge of the problem area under study. The systems designed by analysts whose competence is limited to one or the other field are awesome to contemplate in their myriad array of flaws.

Let us return to the design of a system of services for the mentally retarded. Our first step must be to identify the population. This puts us immediately, and hip-deep, into the business of data gathering. Next we must identify their needs. Whatever special needs the retarded have, they have the same basic human needs as the rest of us, and we must keep this constantly in mind as we struggle to meet their special needs. There is a need for a range of services that includes education, training, and living experiences that facilitate the child's adjustment

to the world around him, by making the maximum use of personal resources within his individual limits.

It must be stressed that we cannot always know what his limits are, and we should proceed with an expectant attitude that avoids self-fulfilling prophecies of failure on the one hand, and unrealistic expectations on the other.

The next group of needs are the social and recreational needs all of us require for a well-rounded life experience. As our client grows older, we must address ourselves to the problems of potential employability, and the training required to develop a marketable skill.

We must now take an inventory of the resources available to provide the needed services, and quality is as important as volume of service. A comparison between the resources available and the resources necessary to meet the needs of the retarded defines a resource gap, the additional resources required.

The appropriate administrative or organizational structure will vary depending upon local circumstances, and any arrangement that gets the job done will suffice. Some mechanisms that may be useful are inter-agency agreements and a centralized referral system.

The result of these efforts will be the design of a coordinated program of services to the retarded. Some estimates must be developed of what can be expected of the program and translated into program objectives, against which program performance can be measured. Then the program should be evaluated periodically and the program-planning sequence recycled to insure that the system is meeting performance goals and remains appropriate to the current need.

The provision of services to the retarded within a mental health setting is actually only a start toward the goal of the provision of all health services to children in one setting, but it is an important step in the right direction away from segregation and fragmentation. Segregation and specialization of programs for the retarded was necessary in the past to establish services, "but duplication and isolated specialization are now creating inefficiencies" (PCMR, 1969).

At least one state we know of - Kentucky - has planned and is developing integrated community mental health - mental retardation centers (Henry, 1970). One of the founders of California's local mental health system noted that in this program, "there is no need to duplicate and have separate services for the retarded" (Hume, 1967). Four years ago a local council of over one hundred

professionals strongly recommended "that community services for the retarded be strengthened and expanded through the ..." community mental health program (S. F. Coordinating Council, 1967). However, most California local mental health programs missed the boat partly through abdication of responsibility and neglect of the problem. A massive parallel system for the retarded then emerged, bringing with it new costs and new strata of bureaucracy. There is reason to believe, in light of recent trends in comprehensive health planning, that this parallel system is actually a backward step since it represents an additional fragment in what will eventually be a unified health system. Other states may wisely avoid this duplication of effort.

It is possible, making use of available methodology, to design, plan, and implement more effective systems of delivering services to the retarded. The inclusion of fully integrated services for the retarded within or under the administration of local mental health centers can significantly improve services to the mentally retarded, when the program is properly designed.

Though community mental health programs could provide services to the retarded, it appears that neither these programs nor any other segment of the population involved with the management of mental retardation is yet ready to work toward eliminating the several existing impediments to the provision of such services through community mental health programs. Are the impediments too big or the motivations too small?

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